Chapter 11

In it for *The Long Run*: Researching Mental Health and Illness

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Abstract

In this chapter we share some lessons we have learnt through doing research *with* – rather than *on* – people experiencing a range of mental health problems. Our work has taken place within social, cultural, economic and political contexts which create several problems or challenges. Through an extended dialogue, we explore how we have critically responded to each of these challenges across three phases of our projects: accessing and witnessing experiences of mental illness; understanding experiences of mental illness; and communicating mental health research. Our aim is to stimulate creative responses to the question of how to do and disseminate research that is most likely to be helpful to people experiencing mental health problems.

Keywords: arts-based research, mental health, narrative, physical activity, qualitative methodology, sport

In it for *The Long Run*: Researching Mental Health and Illness

Introduction

In this chapter we share some reflections on our research in and around mental health and illness over the past two decades. This work has taken place within a social, cultural, economic and political context which – as our discussion will reveal – has influenced the focus and methodologies of our studies. We do not see mental health as located 'in' the individual – determined for example by the person's biochemistry or genetics – but rather as a complex and multifaceted phenomena affected by biographical, experiential, physical, psychological, sociocultural, economic and political factors. Mental illness can happen to any of us. Attending to a range of contextual factors is therefore essential and has, we believe, brought a critical social consciousness to our work.

We begin by briefly considering the broader context within which research into mental health and illness takes place. Existing literature, in particular survivor/service user writing (e.g., Chadwick, 2009; Davidson, 2003; Grant, Biley & Walker, 2011; Repper & Perkins, 2003), has raised a number of issues which can be understood as challenges or problems with existing mental health research and practice. In what follows we summarize those that have been most important in our own work. Inevitably, within the space constraints of a single chapter, we must paint with broad brushstrokes with the aim of providing a contextual backdrop to situate the more personal discussion which follows.

Misunderstanding

An issue that many with mental health problems – as well as their family members and mental health professionals – have to confront is widespread misunderstanding around

mental health and illness. One lingering misperception, for example, is that mental illness is caused by a biological, chemical, genetic or temperamental deficiency, deficit or absence. Further misunderstanding abounds concerning what it is like to experience mental health difficulties. Alec Grant is one of a number of writers who have argued that misunderstanding is based on and perpetuated by a reliance on traditional scientific research methodologies which fail to get close to the lived experience of mental illness (see Douglas & Carless, 2017; Grant, Leigh-Phippard & Short, 2015). Distanced and allegedly 'objective' and 'neutral' research conducted within positivist and post-positivist paradigms has consistently marginalised the voice – and thereby the personal experiences – of people with mental health problems. To remedy misunderstanding it is therefore necessary not only to include but also – at times – privilege the personal voice within mental health research through, for example, artistic (e.g., Chadwick, 2001), narrative (e.g., Etherington, 2003) and autoethnographic (e.g., Grant, 2009) approaches.

Stigma

Stigma is often identified as the biggest single problem faced by people diagnosed with a mental illness (Deegan, 1996; Repper & Perkins, 2003). The obstacles, barriers and challenges created by *others'* negative attitudes, expectations and behaviours can be even more debilitating than the illness itself (Chadwick, 2009). In Peter Chadwick's words, "The plight of many schizophrenia sufferers and indeed the attitudes of the public towards them is a disgrace the Western world. We see here how ignorance is the fuel of fear and prejudice" (2009, p. xi). Tied as it is to misunderstanding and ignorance, stigma is often enacted through a process of 'othering' whereby victims are separated, isolated, alienated and excluded. Rogers and Pilgrim (2005) document how this has been the case for people experiencing mental illness who have been constructed in the scientific literature and portrayed in the

media not merely as different, but often as deficient, deviant and/or dangerous. These erroneous perspectives fuel stigma and hamper the personal and professional prospects of those who live with mental health problems. To rectify the situation it is not people with a mental illness who need to change, but society as a whole.

Diagnostic categories

Mental illness is often seen as synonymous with the presence of symptoms afforded particular diagnostic categories (such as schizophrenia, bipolar disorder, major depression). Conversely, mental health is often taken to be the absence of symptoms. This perspective is problematic for a number of reasons. First, diagnostic categories (set out in *Diagnostic and Statistical Manual of Mental Disorders*, currently in its 5th edition) come to be seen as 'existing' in an objective sense as discrete conditions, when they are constructions – blurred, contested and subjective. As Rogers and Pilgrim (2005) point out, "Judgments about health and illness (physical as well as mental) are value laden and reflect specific norms in time and place" (p. 11). Second, by "blinding doctors to factors in their patients' histories that would be obvious to anyone without a psychiatric education, it has prevented the medical profession from addressing patients' psychological and social needs" (Bentall, 2009, p. 144). Third, it has led to those with forms of mental illness that do not align with existing diagnostic categories being ignored, discredited or marginalised. For example, Bessel van der Kolk (2014) highlights how trauma underlies multiple diagnoses and conditions, yet has never been adequately accounted for in the *Diagnostic and Statistical Manual*.

Treatment

Richard Bentall (2009) presents a troubling picture of mental healthcare – in particular psychiatry – in our times. His picture documents how medication has become the

primary line of treatment for people with mental health problems, leading to huge profits for pharmaceutical companies. The efficacy of these medications are demonstrated through a particular methodology (randomised control trials) developed specifically for this purpose. Simultaneously, alternative methodologies better suited to demonstrating the efficacy of other interventions (such as psychotherapy or physical activity) are discredited under the dogma of evidence based medicine. The complex, holistic and multidimensional processes and outcomes of these kinds of interventions are not well-suited to the 'large *n*' standardized protocols of randomised control trials. Further, outcomes may take years rather than weeks or months and are therefore not accounted for through short-term trials. As a consequence, interventions that can and do help people are marginalized.

One example of these processes in action is evident in Chalder et al. (2012). This paper reports a randomised control trial that purported to explore physical activity as treatment for depression. The conclusion of the study – publicised widely in the British media – was that exercise is "no help for depression." A number of thorough critiques (e.g., Ekkekakis, Hartman & Ladwig, 2018) show how this conclusion is not supported by the study. Although there are numerous problems with the study, two key issues negate the authors' conclusion. First, the intervention employed was not an exercise intervention at all, but the *offer* of up to 10 telephone calls (over 6-8 months) and up to three face to face sessions (max. 2 hours total) with a part-time 'physical activity facilitator'. Unsurprisingly, participants did not fully engage with these sessions: average participation was 7.2 sessions (of the available 13) and only 56% received what the authors term an "adequate dose" (p. 4). Second, neither physical activity measurement (e.g., using accelerometers) nor observation (e.g., through fieldwork) took place. *Actual* participation is therefore unknown. Instead, self-report diaries suggested that 52% of the intervention group achieved high levels of physical activity (≥1000 metabolic equivalent of task minutes a week) at the 4-month point. This

figure appears high and at first seems to suggest the intervention increased exercise participation. But 43% of the comparison group also self-reported this level of physical activity at 4-months. The difference was not statistically significant. It is noteworthy that the comparison group had access to "any treatment usually available in primary care" which included (alongside antidepressants and counselling) "referral to 'exercise on prescription' schemes" (p. 2). It seems as many as 43% of them took advantage of these schemes! Thus there is no basis to draw the conclusion that exercise is not helpful: *both* groups were physically active and *both* experienced modest reductions in depression scores.

A more correct conclusion from this study would have been: *telephone and face to face physical activity consultations do not further reduce depression scores for those already accessing primary care interventions for depression (antidepressants, counselling and/or exercise on prescription schemes).* The unsupported and misleading conclusion that *was* publicised in the media (exercise is "no help for depression") is an insult to those who *do* find physical activity helpful. It is also potentially de-motivating and discouraging to millions of people struggling with depression. Being a RCT none of these people were given an opportunity to voice their counter-experiences – either during or following the research. Instead, their voices were silenced by the more powerful and privileged voices of the nineteen academics who conducted the research and co-authored the paper.

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We are not alone in recognising that critical methods are needed to respond to these (and other) problems in mental health research. In what follows we share some of the lessons we have learnt through doing research *with* – rather than *on* – people with a range of mental health problems. We present our reflections in three sections and in the form of a dialogue through which we explore how we have tried to meet and respond to the above challenges. We use a dialogical (Frank, 2010) writing style, sometimes referred to as *duoethnography*

(Sawyer & Norris, 2015), to preserve our own unique voices and the relational and collaborative way through which our understanding (and, sometimes perhaps, misunderstanding!) develops. We offer these personal reflections with the aim of stimulating creative responses to the question of how to do and disseminate research that is most likely to be helpful to people experiencing mental health problems.

Accessing and Witnessing Experiences of Mental Illness

In the previous section we reviewed some of the challenges or problems with mental health research that have been identified in existing literature, particularly survivor/service user writing. In this section we reflect on how we've tried to navigate, respond to or overcome these challenges in our own work by exploring alternative ways of accessing and witnessing people's experiences of mental health and illness.

David: I think we would both agree that it is important to get close to the experience of mental health and illness if we are to more fully understand it and provide a necessary counterpoint to the distanced scientific gaze. A significant challenge though is *how* to do this. It's not easy! How have you responded to this challenge Kitrina?

Kitrina: Well our first lesson was that some people *can* talk and tell you – they can eloquently describe their mental health difficulties and what has happened in their lives connected to those. Colin is one example (see Carless & Douglas, 2010). He was willing, able and happy to talk about his experiences in great depth. He seemed to enjoy sharing accounts of his life with someone who listened and cared. His descriptions were rich, insightful, visceral, compelling and challenging. We've had interviews and focus groups with others who have also done that. In these circumstances methods such as life story interviews work very well. We listen and learn. But not everybody can share in those ways.

David: That's true. And there are many potential reasons why. One is that some participants don't feel they have a story worth telling. Perhaps experiences of being stigmatized or abused, or what has happened to them over time in mental health services, have led them to lose faith in the worth of their experiences, their stories or themselves. Mainstream culture has tended to silence trauma stories and communicate to the individuals concerned that these kinds of stories are not welcome. A second reason is that some experiences – particularly concerning severe mental distress, trauma or 'madness' – may not be amenable to narration (Stone, 2004). How can a person put such extreme suffering into words? How can I verbalize anguish, hopelessness, chaos, terror? Perhaps I cannot. If we *only* use interview based ways to access and witness then these avenues of human experience will remain unheard, unexplored and absent from our scholarship.

Kitrina: Even when people are able to tell, there can be a personal cost to the telling which makes it very difficult to share. One example is Ben asking a mental health professional to speak to you about things he didn't feel he could voice (see Carless, 2008). Another example is Laura who told me – and showed me – how she had been quietly tearing her nails under the table throughout our interview as a way to 'get through' talking about traumatic experiences (see Carless & Douglas, 2010).

David: So an important question we have faced in our mental health research is what do we do about including those experiences that can't – for whatever reason – be put into words? We've seen this happen so many times. One example (see Douglas & Carless, 2010) was Andrew who when he stood to tee off was trembling so much he couldn't put the golf ball on the tee. Another was William who had sores on his legs that looked really painful – he would scratch them and we could see them bleeding during activity sessions. I felt uncomfortable asking about these things as they seemed so personal and sensitive. Neither Andrew nor William voiced them. Yet both these physical manifestations are recognised

side-effects of long-term use of antipsychotic medication. So we need to include these experiences in our research – they are relevant and significant personally, culturally and politically.

Kitrina: One of the most important research strategies we've used to get round these issues is spending time *with* people – in the day centre, on the bus, at the driving range, in the café, on the golf course. It was more than just 'being there' (Wolcott, 2002), more than participant observation as its described in methods texts. Yes, we were there. Yes, we participated. Yes, we observed. But we also became part of the furniture, engaging in reciprocal, caring, human relationships with those who attended the day centre.

David: Once again *we* needed to change – in this case how we *do* research. The participants showed us how we needed to be and helped us find a different way of doing mental health research…

Kitrina: … a way that is necessary if we are to produce new findings that are insightful, helpful and critically aware …

David: … and essential when it comes to a sport or physical activity intervention. We are *intervening* in people's lives for goodness sake! We're asking them to do something differently. That sounds quite arrogant. If we are going to do it we should, at the very least, ensure we have a pretty comprehensive understanding of their lives – their problems and possibilities, fears and wishes. Without that we are on ethically shaky ground even considering trying change other peoples' behaviour.

Kitrina: Things that to us, from a distance, might seem easy can be much more problematic for a person routinely experiencing high levels of mental distress. Laura described how participating in a badminton group in the context of bipolar disorder was like trying to run loads of different software on your laptop all at once (see Carless & Douglas, 2012). The result? Overload. Everything just grinds to halt.

David: That's what attending an activity group was like for her: she crashed before she'd really got started.

Kitrina: Another good thing about being with participants in their environments is we are *available*. Participants can access the researchers when *they* are ready to share. And a person might not be ready to talk for a long time. And she might not be ready to talk when *we* want her to talk, when the recorder is running. With Ana, it took four years to disclose a history of sexual abuse (see Douglas & Carless, 2012a, 2012b). It took that long to bridge the silence, for things in her life to conspire to lead her to disclose. For Ana it was: *now* I want to speak about this. If I hadn't been continuing the research and interested in the participants over those years, we would never have learned of the cause of her mental health problems.

David: Her story would have remained silenced.

Kitrina: All of these things needed *time* – time to develop, time to be spoken, time to be witnessed, time to be understood and time to be communicated to others. We couldn't just go in with our research question, stick to that, and expect to get real insights.

David: We've needed to be open to being in the research for the long run, with participants, engaged in sustained reflection, analysis, interpretation, representation. Otherwise – especially in an area like mental health – we are likely to produce studies that are shallow, misleading or simply wrong. There is a real danger that questionnaire or 'one-shot' interview approaches miss the heart of the issue by failing to get sufficiently close to people's experiences. They don't do enough to support service users to speak, to amplify their voices. The result: dominant stories of mental illness are uncritically reproduced.

Understanding Experiences of Mental Illness

David: We've talked about different ways to access and witness people's experiences of mental health and illness. As researchers, we are then faced with the question of how to document and make sense of what we witness. A questionnaire is documented in the act of being answered. A formal interview or focus group is documented – to a degree – through the act of being recorded. This isn't the case though for fieldwork. Taking our golf and mental health project (see Carless & Douglas, 2004, 2008; Douglas & Carless, 2010) as an example, what did you do to document what you'd experienced?

Kitrina: What we *both* did was commit to going back to the university after we'd finished to write up field notes. It was something I really didn't want to do!

David: It was hard wasn't it? I already felt exhausted from the fieldwork – to then sit there for a couple of hours writing was almost too much.

Kitrina: We'd been giving out a lot. It takes huge energy to, first of all, plan the session and every detail, deliver it, and then attend, notice, listen and witness for a day – or even a half-day – of fieldwork. So although I had to force myself to write at the time, the process was really beneficial. Reading back our field notes later, it was like, *"Whoa! There's so much here!"*

David: For me it was essential. Doing fieldwork, I notice important things happening but if I don't document them pretty quickly, they're gone. The 'highlights' might remain but the detail will be lost. What writing forms do you use to do that?

Kitrina: Although its not always practical, I try to keep brief notes during the fieldwork if I can. It might just be one word to remind me of something or prompt me to things that happened. But if you think back to the fieldwork, so much happened in the four hours we were on the golf course. It was like I wanted to flood it all out, but I couldn't get it all on the page fast enough. As fast as I was writing it down I was forgetting it! So I started

off with bullet-points, shorthand, one-line notes which I could later develop. What writing forms do you use?

David: I suppose I try to document and reconstruct moments that strike me as significant. The best way to do that I've found is through telling a story. I tend to write in the first person *I* – and I will be present in the story so the events are filtered through me. I'll try to recreate what I witnessed or participated in with these particular people at that time, what they said to each other, their expressions, embodied interactions and what any consequences were. Always trying to preserve and communicate the context and environment.

Kitrina: Any other approaches?

David: In the military research (e.g., Carless, 2014; Carless & Douglas, 2016, 2017), while I was doing fieldwork it sometimes happened that a soldier would start to talk to me – at the climbing wall, say – about their experiences. The participant initiated conversation, sharing something of their life, outside a formal interview situation. And often what they had to say under those circumstances was more insightful, powerful or revealing than what I heard during planned interviews when my recorder was running. So if a person volunteered a story in this way – at a time and place and in a form that suited them – I wanted to include it in the research because it usually had loads to offer. I settled on working to recreate from memory what they had told me, staying as close as I could to the individual's language, expressions, vernacular, forms of telling. So again the stories are in the first-person, but this time the *I* is the participant. Over time, I'd then develop the story as subsequent conversations unfolded during the fieldwork, adding, extending and enriching the account. Then the final stage was to share the story with the individual, engage in dialogue and, if they were willing, collaboration to refine the story. That seemed crucial ethically – to involve each participant in the creation of 'his' story and check he was happy with 'his' words on the page. We ended up with a series of concise personal accounts, akin to testimonies. What about your approach

Kitrina? I've noticed when you write stories from research they are often in the third person – so you are a character in the story but you are 'she' or appear under the pseudonym Jessie.

Kitrina: I never start with Kitrina! I see the events as a scene, as if I'm watching a movie. I try to describe what's going on so the reader can also see what's going on, be a fly on the wall. I'm trying to get the essence and feel, rather than just replicate what somebody said as a recording would. Although I do want to stay as close to it as I can, I recognise I can't reproduce it fully, and that's not what I'm there to do. What I'm there to do is communicate something that was powerful and left a residue.

David: There's always too much happening, not only to notice but also to write. So you're always distilling and focussing on key moments. I like what you said there about prioritising what it *felt* like. I think we both write to offer a vicarious experience to the reader even though, of course, no-one *can* experience the events – they've happened, they're gone. But by writing well, the reader can get a feel for what was significant or important in that moment.

Kitrina: Often there's something that left a mark on me and I'm trying to leave that mark on the reader through what I write.

David: That's a nice way of putting it. We started off talking about the importance of what we notice in our embodied selves. But how can we document that? Stories offer one very human way. We could document events by filming with a video camera, but it wouldn't catch these kinds of subtleties. Even if we had a satellite overhead recording 'everything' it wouldn't catch this stuff. It's a human, artful sensitivity and sensibility to draw out what is critical and to recreate it, to show it to others.

Kitrina: We're talking about mental health and illness – you cannot see that, document it, from the outside. To get at that we need to get up close to 'see the inside' – we need to interact with, come to know, listen, witness, and learn from each individual.

David: When it comes to processes of understanding, making sense, we were both initially trained in scientific research methods where the prevailing view is that you have to have understood – you form this knowledge, hold it in your brain – *before* you write. The accepted view is: to be able to write you must have already made sense of what you're writing about. But that absolutely is *not* the case when we work like this. As we write stories its not just that we are showing another – the reader – what we know, but through the process of writing we are showing *ourselves* too. So by writing in these ways we can come to know and understand in a deeper and richer way something that, prior to the writing, we might not even have known existed.

Kitrina: I agree. But this takes time and requires openness. Students and novice researchers often feel they must have specified a plan when they begin a study. So they plan in advance particular questions, a content analysis to create themes and categories – and it all sounds do-able. I think we're saying, well, you *can* do it that way. But if you go and *be there*, and begin to notice, begin to feel, that can provide something else that is very important. There's always so much going on that is relevant, but you won't know the relevance of it to begin with. That's when you have to trust that something is happening even when you might not have appreciated its significance yet. It's a bit like when you put cake ingredients together, it's all just a mishmash – flour, eggs, sugar, raisins. You throw it all together but its not a cake! Its just a load of ingredients. But then you stick it in the oven and you trust that during the hour its in there it'll rise and turn into a cake that's edible. But if you can't trust and allow the oven to do the work, its just a load of sludge.

David: So its learning to trust yourself – your *self* in the broadest sense of body, mind, spirit, emotions – and allow the processes of understanding the time they need to unfold and reveal.

Kitrina: But everything in our culture – certainly in academia – tells us the opposite. Researchers are often pressured to be 'efficient', produce 'outputs', often in a short time scale, neatly packaged and tied up. But the criticisms around the way mental health research is often done call us to pause, reflect and say 'Hang on a minute!'

David: Particularly when we are talking about mental distress, when experiences can be chaotic, when things *don't* necessarily make sense (see Baldwin, 2005). The life circumstances of a person experiencing mental illness can be hugely complex. How *can* we understand and make sense of that? Perhaps the first realisation is it might not be possible to. There's a danger that we, as researchers, make things too neat, finalize and get it wrong.

Kitrina: Exactly. At times – especially in this area – we need ways of understanding that are able to tolerate messiness, chaos, ambiguity, uncertainty, while at the same time allowing something meaningful to be learned regarding some of the most challenging human experiences.

David: Through doing mental health research, working alongside and learning from people experiencing mental health difficulties, we've gradually come to realise that the nature of the knowledge that is needed does not fit well with the accepted forms of analysis and representation within the science and social science world. The methods and approaches needed to do justice to and help people are often not accepted or valued within traditional frameworks.

Kitrina: Other ways of understanding, making sense, are needed. Like arts-based, storytelling, performative, autoethnographic and film-based approaches. I think all these will have an increasingly important role to play in the future.

Communicating Mental Health Research

David: We've talked about ways of generating empirical material and alternative ways of making sense of those materials. What is at the forefront of your mind when you come to consider how to communicate your work?

Kitrina: I suppose I'm looking for things that have moved me, emotionally. That signals *something is there*. Then I'm considering different forms I might use to communicate with someone else. At my disposal I've got stories, songs, poetry, film, music. One form might work in one case but not another so its not about saying one is 'better' than another. It's more about experimenting with different genres to find what works for this particular project.

David: The first thing you said then was looking for things that moved you. Why is that important?

Kitrina: Because my emotional response marks times when I have been affected by something. Perhaps its something I haven't seen before. Or something I've learnt. Maybe I've experienced an 'a-ha' moment.

David: So its a case that something has happened at those moments to challenge what you know?

Kitrina: Or what I *think* I know.

David: You're looking for things that challenge you, your existing knowledge, what you've seen, or what's in the literature?

Kitrina: Yes, any and all of those. Is that how it is for you too?

David: When we are involved with a project for a long period of time there are many realisations and they dawn slowly. But we can't communicate everything. So I look for concise chunks to show something that might have taken weeks, months, even years to come to. I suppose I'm looking for the empirical moment. I don't want to just say *this is what happened*, I want to recreate *an illustration of what happened* to show readers in the way I

was shown. So for *The Long Run* (Douglas & Carless, 2014), Ben told me a story about running the Bristol half-marathon and the story *showed* me running's importance to him.

Kitrina: What you said then – I think – is you want to show the steps that led you to that insight. By recreating a 'nugget' that led to that understanding, somebody else can come to an understanding too. That's definitely what I try to do.

David: There's a desire to be democratic and humble in that. I don't always get it right. But rather than trying to *persuade* an audience – arguing in the way barristers do by presenting or withholding evidence to make the case they are paid to make – I want to present events in a way that allows someone to come to their own interpretation. I also want to allow the possibility of someone seeing something that I haven't seen that is relevant to their life, their experiences or their professional practice.

Kitrina: I think that's important. We're not just stating A, B, C. We're painting the picture and although we can only point the camera in one direction at a time, we're trying to do it in such a way that it leaves opportunities to interpret and explore other things that are in view and might be relevant to others.

David: We both often have strong views on things – such as the awful side-effects of antipsychotic medication. We're positioned politically and ethically, we have an agenda. But we also try to come off that and not *only* present one view of the situation.

Kitrina: What came to mind as you were talking is something we were aware of when we began our mental health research: positive and negative symptoms. The idea of things you *get*, and other things that are *taken away*. When I was filming *The Long Run* I was really struck by the number of people who linked hands to cross the finishing line together. I was blown away by seeing and filming the last 100 meters of that race. I felt such a strong sense of connection and togetherness. Yet that is taken away from you if you experience long-term mental illness, especially if you are institutionalized. Social isolation, alienation, separation –

these are such debilitating negative symptoms. And it was only as we were making the film that I felt the power and importance of that.

David: So several years after the interviews you went out to record footage and it was that which cast a new light on what you'd previously understood. That really makes sense with negative symptoms – things that are missing from people's lives. Is anyone in a position to narrate absences, what is *not?* How can we show and talk about things that are missing? Filming a community event provided an opportunity to grasp and communicate that issue. And it is significant that it was a particular image – what you saw looking through the viewfinder – that crystallized the point.

Kitrina: And it links to Ben's story: "We did it!" Many of us have that kind of experience in our lives and it's important. But this is often denied by the experiences surrounding mental illness. Historically, there have been a paucity of stories of success and achievement for mental health service users (Repper & Perkins, 2003). Dominant stories have tended to be negative, debilitating, limiting and hopeless (see Deegan, 1996).

David: Yet people with mental health problems can and do transcend their problems (see Chadwick, 2009). When we were learning about Barbara Hepworth's work I was taken by her commitment to make sculpture that is *affirmative*. I want us to work towards that through our research representations.

Kitrina: The Bristol runners were getting and doing affirmation – their success was public. They were being applauded by the crowd and acknowledged. There is something about being validated within your community. You can't claim an identity unless it is in some way acknowledged or validated by others. Hilde Lindemann (2014) talks about that – we can call ourselves whatever we like but if nobody else recognises us as a doctor we are not a doctor!

David: As we think about representation we're also asking: Are these new stories which offer narrative resources to allow others to see themselves in affirmative ways? At the same time: do they help others see them in more enabling ways?

Kitrina: You had already written *The Long Run* story several years before for your PhD. In terms of communication, you had already communicated it. But it seems to be amplified in the film. The images, sounds and music seem to provide an additional touchstone to help people connect to it.

David: One of the problems in research – that I too have at times been guilty of – is a tendency to take an individual and place them on a real or metaphorical microscope slide. Whether its through brain scans, muscle biopsies, questionnaires or life story interviews, the individual is the focus. That can be valuable – it offers certain insights. But it simultaneously tends to construct the person as an isolated being. *The Long Run* is a monologue, the nature of which means the person speaks alone. While we have retained the monologue as the spoken part of the film, the way you've included shots of different people and groups, sounds, music, the words of the songs, the way you've edited it, all helps preserve a sense of this person's connections. Ben seems less alone somehow. That is important because even the person who is experiencing the most severe forms of distress still has connections. And that person needs to know those connections exist.

Kitrina: Even as a viewer I feel that connectedness – I can't help put myself into the picture. I feel I am there. I'm *with* Ben. *I'm* running the race.

David: Me too. So what would you say is your priority – your overriding purpose – when deciding how to communicate your research?

Kitrina: Personally, I am very humble about any aspirations I have for our research. I start with: can I help one person? I go to the one person and try to honour what they have offered by giving everything I've got – my skills, my intuition, my understanding – to create

something that works for them. Then I go on to the next person. So its bird by bird. Over the course of twenty years we've learnt that our first port of call should be the participants. Is this working for them? Are they getting anything from it? Then we have to show something to the funders which is a different dynamic. But my heart is at the community level – to make something ordinary people can access. So the possibilities of YouTube are immense, and free-to-view films are a great way to realise our goal of offering information in a form people can access, 'get' and use in their own lives.

David: I think what's been a constant for us – and will be now for as long as we work – is the desire to make what we have to say accessible to anyone. We're researching things that don't just affect experts, policymakers and professionals. These are issues that affect us all. The figure we hear is 1 in 4 have a mental health problem. But its probably everybody at some point in their life. When we add negative attitudes towards people who have mental health problems that provide a basis for stigma – that any of us can slip into – its clear we're all part of the problem. Everyone. Society, communities would be better if *all* of us took this on board. So we want to find ways to communicate our research that are accessible, engaging, democratic. That's something I learnt from presenting the early stories from my PhD research at conferences and events for service users, carers, family members, mental health professionals. Right from the get-go, again and again, people valued the insight, emotion and power of personal testimony. The first time I performed a story one woman stood up and, shaking with emotion and close to tears, in front of an audience of 200 said: "Thank you for being the only person here today to talk about people." This kind of work is relevant to people's lives. Responses like that stay with me – they give me a huge incentive to continue.

Kitrina: That was really moving for me, when you came back from a talk and a mother had said, "That's my son. I recognise that story. That could be my son in there." To be able to let that person feel they are not alone, they are not cut off from society, that

someone understands, that people do care. For me, this is where we must start, by asking ourselves: How can we do this research in such a way that it will reach those who need it, in a connected and affirmative way?

Conclusion

We have covered a lot of ground in this chapter, from broadly considering the cultural and political contexts within which mental health research takes place, through to detailed reflections on the lessons we have learnt through *doing* mental health research in sport and physical activity. While many conclusions could be drawn, the key one for us is to underscore the need for research which allows sustained involvement, immersion and engagement with the experiences of people living with and through mental health difficulties. To do good, useful, helpful, ethical research in this field it is clear to us that researchers must indeed be in it for the long run. At this point on our own research journeys, we have committed to doing this through a range of arts-based methodologies which support critical, democratic, accessible and insightful social and psychological research. The three waves of engagement (see Douglas & Carless, 2018) that typify our own research process (interdependent engagement with people and place; aesthetic engagement with sense making processes; emotional engagement with – and of – audiences) connect directly to the dialogues we have shared above. We invite you to consider these alternative approaches to researching mental health and illness and, if you so wish, to join us on the journey.

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